

Psychological and Social Needs

Early Stages of Dementia

Goal

- Person enjoys optimal psychological and social well being

Key Assessment Issues

General

- Person is aware of declining abilities in early stage and may try to mask by compensating/covering up strongly (e.g., making jokes, excuses, blaming others, using others to cover, etc.)
- Psychosocial symptoms/difficulties are some of the first changes to be noticed in early stages of Alzheimer's disease and related dementia
- Person may have periods of frustration where concerns or fears are expressed
- If diagnosis is made, person may have conflicting feelings, continued denial, fears of becoming a burden to others, loss of ability to be useful and contribute, etc.

Judgement of Ability

- Person may deny that they are having problems, refuse discussion, or become anxious/agitated when problems are revealed

Emotional Issues

- Person may experience a variety of emotions – sometimes in mood swings including denial, anger, frustration, fear and/or depression

Possible Interventions

General

- Person's denial of having problems, especially when inconsistencies are brought up, is a red flag. Concerns can be communicated to person's health care provider (e.g., physician, nurse, social worker, therapist, etc.), and short cognitive screening exercises (e.g., Folstein Mini Mental) could be worked into a routine appointment
- If difficulties are discovered, it is important to support the person, encourage a formal evaluation, and help him to understand that reversible causes for problems are frequently discovered, and if Alzheimer's disease is diagnosed that cognitive enhancing medications can be used to arrest or slow decline in a worst-case scenario (the earlier started the better they work)
- Encourage the person to obtain appropriate explanation of what is happening through thorough medical evaluation and conversation with physician if person is willing to admit to/discuss their decline (see care planning area # 3)
- Encourage and support acceptance process at the person's own pace

Judgement of Ability

- Encourage people closest to the person to communicate their concern, caring and support to the person instead of arguing or confronting. Encourage person's supporters to educate and get support for themselves (see care planning area #2)
- As part of communicating concern, provide written information to the person about the symptoms and where to ask questions or obtain help/advice when ready

Emotional Issues

- Validate person's feelings of denial, anger, frustration and grief, offer support and understanding
- Insure completion of evaluation and treatment of depression, anxiety, etc., if indicated
- Suggest counseling, if indicated
- Refer to Alzheimer's Association for support, education and consultation

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Psychological and Social Needs

Early Stages of Dementia (continued)

Goal

- Person enjoys optimal psychological and social well being

Key Assessment Issues	Possible Interventions
<u>Emotional Issues</u> <ul style="list-style-type: none"> • Person may experience apathy, lack of initiative and/or decrease in ability to have emotional responses as a part of the disease process • May recognize losses and experience emotions associated with grief <u>Social Relationships</u> <ul style="list-style-type: none"> • Person may begin to withdraw from social situations and usual activities • Mood/personality changes, outbursts may make person seem they aren't "themselves" • Changes or help offered to the person may result in accusations, false statements and/or suspicion of others <u>Complex Tasks</u> <ul style="list-style-type: none"> • Person may skip or forget parts of routine activities (e.g., going to religious services/clubs, forgetting to clean/bathe, etc.) • As a result of feeling a loss of control, person can become preoccupied with having control or with items that symbolize it (e.g., keys, driving, fixing own food), and become very agitated when others try to change/interfere with these items or activities <u>Communication</u> <ul style="list-style-type: none"> • Person may forget what she said or what was told to her frequently – sometimes within a very short period of time • May experience confusion, be unable to follow conversations or may misrepresent past events 	<u>Emotional Issues</u> <ul style="list-style-type: none"> • Encourage the person to identify a trusted family member, friend and/or professional to discuss feelings with and gain support from • Encourage person to participate in early stage support group • Encourage person to begin planning for the future, e.g., doing things he always wanted to do, identifying future adaptation strategies and care preferences, etc. (see care planning area # 6) <u>Social Relationships</u> <ul style="list-style-type: none"> • Encourage family and friends to keep open communication and to validate person's feelings, avoid arguing - advise family on how to educate others about person's changes • Continue with social activities as tolerated within usual groups, or modify group size to provide more individual attention within group as needed • Utilize natural supports (existing friends, neighbors, family, clubs, congregations, etc.) and/or senior center activities to maintain connection to life and involvement with others <u>Complex Tasks</u> (also see care planning area #1) <ul style="list-style-type: none"> • Recognize importance of these items/activities to person. Consult with person about these items and build in ways to support person's independence, offer choices • Refer family to consult with physician and Alzheimer's Association on driving ability and getting support for strategies to give up driving (see care planning #1, #3, #7) • Encourage the person to focus on strengths, enjoyment and continued capabilities, provide assistance where needed <u>Communication</u> <ul style="list-style-type: none"> • Write down and date important information, then go over it verbally to assure understanding – post it in accessible place • Do not correct person or argue. Instead realize what she thinks or feels is her reality and act accordingly • Focus on asking about person's feelings and experiences, not on recalling facts, have a sense of humor about things

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Psychological and Social Needs

Middle Stages of Dementia

Goal

- Person enjoys optimal psychological and social well being

Key Assessment Issues	Possible Interventions
<p><u>General</u></p> <ul style="list-style-type: none"> • Person's frame of reference to time periods will shift from the present to living in the past • Person will likely lose insight into problems. May focus on things that were problems in the far past as if they are current as "repetitive themes" • May experience boredom and isolation due to increasing inability to self-initiate purposeful activity <p><u>Emotional Issues/Symptoms</u></p> <ul style="list-style-type: none"> • Person is more sensitive to other's emotions, expressions and moods due to loss of reasoning skills • Person's expressing or showing signs of anger, frustration and depression may appear to be unprovoked • Signs of worry, anxiety, even panic especially in overwhelming, chaotic, or unfamiliar situations may occur • Person may have a lower threshold for tolerating triggers to memories of previous trauma and go back to it • May experience hallucinations, sexual response changes, paranoid feelings • May pace or appear to walk around aimlessly (usually from boredom, lack of involvement) <p><u>Social Relationships</u></p> <ul style="list-style-type: none"> • Person can easily misinterpret environment and other people's words and actions • Has decreasing ability to empathize, show concern for others 	<p><u>General</u></p> <p>It is important to consciously enhance the person's quality of life and self esteem at this stage. <u>Suggestions:</u></p> <ul style="list-style-type: none"> • Encourage caregivers to accept the person's reality and act accordingly, providing validation and reassurance • Incorporate the person's preferences into care, adaptations • Focus on person's strengths, not deficits • Compliment and praise person for things she can do, no matter how small, celebrate successes • Encourage involvement in life, doing things person enjoys • Ask person about her thoughts and feelings, not to recall facts which would focus on her memory disability <p><u>Emotional Issues/Symptoms</u></p> <ul style="list-style-type: none"> • Encourage pacing the environment between fun, interactive and stimulating periods to eliminate boredom - and calming, familiar, comfortable environments that reduce anxiety for the person and reduce tension for the caregiver • Assist caregiver in learning to relate to issues behind the person's feelings rather than relying on words • Encourage the caregiver to be observant of and acknowledge all feelings the person is expressing, and to ease those which cause the person emotional discomfort • Monitor environment when behavior symptoms occur, assist in planning adaptive responses and environmental changes to minimize behavior in the future (see care planning area # 7) • Teach strategies to de-escalate and minimize or eliminate triggers for the person by shifting activities and responses as difficulties arise, also rule out medical causes (see planning area # 3) <p><u>Social Relationships</u></p> <ul style="list-style-type: none"> • Utilize games, pictures, props, etc., to enhance and create positive interaction during visits • Help caregivers realize not to take person's actions or comments personally when behavior symptoms occur - teach strategies for moving past awkward moments and maintaining a sense of humor

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Psychological and Social Needs

Middle Stages of Dementia (continued)

Goal

- Person enjoys optimal psychological and social well being

Key Assessment Issues	Possible Interventions
<u>Social Relationships</u> <ul style="list-style-type: none"> • Person may mistake people for someone in his past, may not recognize familiar friends and family • Person can enjoy and benefit from activities with others that allow him to participate creatively <u>Complex Tasks</u> <ul style="list-style-type: none"> • Person may resist assistance • Has decreasing ability to individually plan and carry out activities and social involvement • Has a great need to feel she is still useful and contributing to others lives <u>Communication</u> <ul style="list-style-type: none"> • Person has decreasing ability to initiate conversation or interactions with others - may appear self-absorbed • Has increasing difficulty accurately expressing needs verbally. May be preoccupied with finding familiar things from childhood (mom, dad, siblings, wanting to go home, etc.) when she has unmet needs 	<u>Social Relationships</u> <ul style="list-style-type: none"> • Encourage family, friends and caregivers to initiate caring interactions with the person and to continue the essence of a normal relationship • Plan and involve person in activities and social situations that continue past interests and lifestyle even though the activity may need to be adapted (see care planning area #1) • Encourage adult day service participation for person to have opportunities to remain active, involved and using abilities if possible/appropriate (research shows mood, health and sleep are improved too) • Inform caregivers and family of discrete ways to alert others in social situations that the person has dementia (e.g., business sized cards from Alzheimer's Association that state person you are with has dementia, etc.) so they can work together to make situation go smoothly <u>Complex Tasks</u> <ul style="list-style-type: none"> • Help caregiver understand that what works today may not work tomorrow, to keep trying new things • Encourage person's continued participation in daily tasks/activities (doing them "together") e.g., meal prep, laundry, etc. - so person can feel and see she is contributing • Break down tasks into individual steps and guide, praise and compliment efforts regardless of success, thank person for assistance <u>Communication</u> <ul style="list-style-type: none"> • Work with caregivers to develop specific supportive communication techniques, e.g., validation by accepting the person where they are, seeking to understand more and build trust, rephrasing, letting person lead conversation, etc. • Encourage use of communication aids if needed, e.g., pictures, words or symbols on cards (see care planning #1) • Teach how to enter the person's world with them - initiate reminiscing activities routinely and create a life story book featuring pictures, mementos and other items from the past (see care planning areas #1, #7)

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Psychological and Social Needs

Late Stages of Dementia

Goal

- Person enjoys optimal psychological and social well being

Key Assessment Issues

General

- Person becomes totally dependent on others in order to experience any quality of life – remains capable of experiencing and expressing things
- Lack of interaction with others and environment will cause more rapid loss of skills, expressions and function

Emotional Issues/Symptoms

- Personality and emotional changes continue
- Environment, sensory experiences, presence/absence of physical pain, and touch from others greatly effect person's emotional state
- Person may be easier to startle, can cause catastrophic reactions

Social Relationships

- Potential for social and emotional isolation
- Person is still capable of meaningful interaction with others

Communication

- Person experiences inability to communicate verbally, but shows reactions to/interactions with others and environment; uses words, sounds and body language to communicate feelings, needs and reactions

Possible Interventions

General

- Continue to incorporate person's care preferences as able
- Continue interventions from the middle stage to enhance quality of life, self esteem and well-being as possible
- Take steps to create a pleasant sensory and emotionally stimulating, soothing environment (see care planning area #7)

Emotional Issues/Symptoms

- Assist family in evaluating and promoting comfort strategies, while diligently controlling pain and co-morbid conditions that could lead to pain and distress
- Encourage person to continue using abilities e.g., hold a cup/spoon/ brush, sit up to eat at table or tray, walk, exercise extremities, hum or sing, etc.
- Instruct on how to avoid startling person: standing in front when speaking, be in line of sight before touching, stand beside before pushing wheelchair, whenever out of line of vision tell person where you are/what you're doing, etc.

Social Relationships

- Encourage family/friends to continue essence of relationships through 1:1 visiting—use caring touch, hum, sing, play music, tell stories and reminisce, read aloud, hold or rub hands with lotion, offer sensory things (favorite foods, textures, smells).
- Explain that music remains a powerful means of sharing enjoyment with the person long into the person's illness evoking emotional (sometimes singing) responses

Communication

- Teach caregiver to talk to the person while providing for personal care, or during other interactions, to reassure and continue to relate to the person, i.e., introduce self, explain what you are doing, what is going to happen before it does (e.g., give juice)
- Explain ways to use verbal communication to elicit responses from the person, acknowledging them out loud – regardless of the type of response (sound or gesture) – and then to verbally interpret the person's meaning back as validation of her message

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